



NATIONAL ACTION PLAN ON BREAST CANCER A Public/Private Partnership

F A C T S H E E T

BACKGROUND

Breast cancer is the second leading cause of cancer deaths among American women. An estimated 175,000 women will be diagnosed with breast cancer in 1999, and more than 43,000 are expected to die from the disease.

In 1993, the National Action Plan on Breast Cancer (NAPBC) was initiated in response to the National Breast Cancer Coalition's 2.6 million signature petition calling for a coordinated national strategy to combat breast cancer through public/private partnerships. President Clinton asked the U.S. Department of Health and Human Services to respond, and in December 1993, Secretary Shalala convened the Secretary's Conference To Establish a National Action Plan on Breast Cancer. The conference brought together more than 300 individuals, including breast cancer advocates, consumers, clinicians, scientists, government officials, educators, and members of Congress and the media, to craft a series of recommendations for action in education, research, public policy, and service delivery. From this conference, a Steering Committee of government and nongovernment representatives was formed to build necessary public/private partnerships and to guide a comprehensive national plan to eradicate breast cancer.

MISSION AND STRATEGY

The mission of the NAPBC is to stimulate rapid progress in eradicating breast cancer by advancing knowledge, research, policy, and services. The Plan serves as a catalyst for national efforts, coordinating activities of government and nongovernment organizations, agencies, and individuals. By encouraging new ideas and mobilizing partnerships, the Plan strives to "jump-start" innovative, long-term efforts that will result in rapid progress in the fight against breast cancer.

ORGANIZATION

Reflecting its status as a unique public/private partnership, the NAPBC has one Co-Chair from the public sector and one from the private sector. Frances M. Visco, Esq., President of the National Breast Cancer Coalition, serves as the private sector Co-Chair. Wanda K. Jones, Dr.P.H., Deputy Assistant Secretary for Health (Women's Health) in the U.S. Department of Health and Human Services, serves as the public sector Co-Chair. The NAPBC Steering Committee includes government and nongovernment representatives from research, policy, health care, breast cancer advocacy, and industry organizations. The Committee establishes NAPBC priorities, guides implementation of initiatives, and ensures coordination across priority areas. Six Working Groups were established to identify and implement specific initiatives within these priority areas; one has accomplished its objectives and has sunset. The U.S. Public Health Service's Office on Women's Health coordinates the implementation of activities and oversees day-to-day operations of the Plan.

PLAN ACTIVITIES AND WORKING GROUP PRIORITY AREAS

Information Action Council Working Group

The Information Action Council (IAC) is identifying strategies to disseminate information about breast cancer, using state-of-the-art information technologies available on the Internet. This group developed and continues to maintain the NAPBC Web site, also available in Spanish, which provides information about Plan activities and is a central gateway to breast cancer information on the Internet. In addition, the IAC oversees the Bridging the Gap Initiative pilot project, in which community-based organizations link informationally underserved women with breast cancer information available through the Internet. The IAC also is developing a Web-building toolkit for local breast cancer organizations.

Consumer Involvement Working Group

This Working Group has successfully outlined issues related to the involvement of consumer advocates in all aspects of breast cancer service delivery, education, policy, and research. In partnership with the National Alliance of Breast Cancer Organizations and the National Breast Cancer Coalition, the group developed and implemented surveys to explore the nature of the involvement of breast cancer patients and survivors, their representatives, and those at high risk for breast cancer in consumer organizations and in cancer centers. The Working Group also is preparing to assess consumer involvement in the pharmaceutical and biotechnology industry and relevant Federal agencies.

Breast Cancer Etiology Working Group

The goal of this Working Group is to expand the scope and breadth of biomedical, epidemiological, and behavioral research activities related to the etiology of breast cancer. This group has convened workshops to review the current state of knowledge and to develop research recommendations in the areas of viruses, hormones and the environment, physical activity, medical ionizing radiation, electromagnetic fields and light-at-night, and early life exposures. The group also has developed and focus-group tested the Breast Cancer Comprehensive Questionnaire, a series of high-quality questionnaire modules, along with short and long versions of a core questionnaire, that can be used to clarify emerging risk factors and to enable meta-analyses. Future activities include finalizing and disseminating the comprehensive questionnaire and convening workshops on multi-cultural aspects of breast cancer etiology and the role of tissue architecture in the development of breast cancer.

Clinical Trials Accessibility Working Group

This Working Group is examining ways to make clinical trials more widely accessible to women with breast cancer and women who are at higher risk for breast cancer. It has reviewed extensively the literature on barriers to participation in clinical trials and is developing strategies to overcome these barriers. To implement one such strategy, this group conducted patient and physician focus groups to develop the components of a public awareness campaign about clinical trials. Efforts also are under way to evaluate and improve health care providers' and consumers' access to information about breast cancer clinical trials.

Hereditary Susceptibility Working Group

Members of this Working Group are addressing the fast-moving social, ethical, and legal issues related to genetic testing. They produced and distributed over 30,000 copies of the video, *Genetic Testing for Breast Cancer Risk: It's Your Choice*, and, in partnership with many professional organizations, they developed an educational curriculum, *Hereditary Susceptibility to Breast and Ovarian Cancer: An Outline of Fundamental Knowledge Needed by All Health Care Professionals*. This group also has convened workshops to identify urgent research priorities in breast cancer susceptibility and on privacy and confidentiality in genetics research. In addition, this group is spearheading efforts to establish policies to prevent workplace and health and life insurance discrimination based on results from genetic testing.

National Biological Resource Banks Working Group

This Working Group is the first to accomplish its objectives and sunset. The Working Group advanced efforts to establish a national inventory of biological specimen banks to facilitate breast cancer research. The group conducted a needs assessment focused on determining the nature and extent of the need for biological resources. In addition, the group developed guidelines for the ethical use of biological tissues in breast cancer research, including a model informed consent form and institutional review board principles of operation. These products have been adopted by the National Cancer Institute and Public Responsibility in Medicine and Research, respectively, for further development and implementation.

NAPBC Grant Program

In 1995, the NAPBC awarded \$9.2 million in small grants and grant supplements for innovative research and outreach projects in each of the Plan's six priority areas. Special emphasis was placed on the development of public/private partnerships in the design and implementation of these projects. Project outcomes are being integrated into ongoing Working Group activities. A grants compendium describing the funded projects will be available in 1999.

FOR MORE INFORMATION CONTACT:

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